

West Nile's aftermath: Some who survived virus now battle paralysis
M.A.J. MCKENNA
1543 words
13 September 2004
The Atlanta Journal – Constitution
Copyright (c) 2004 The Atlanta Journal–Constitution, All Rights Reserved

Punkin Center, La. --- When Twila Jean Starkey wants to stand up, she beckons her husband Joe to the front of her wheelchair.

He bends, and she wraps her arms tightly around his neck. He straightens slowly, taking her weight on his torso until she is upright. Then he places his hands on her hips and backs her into place.

The Starkeys look like they are dancing --- but they have not danced together in two years. In July 2002, Twila Jean became one of the first cases recognized in the United States of a new form of paralysis, one that looks like polio but is caused by West Nile virus. According to the Centers for Disease Control and Prevention, several hundred Americans are believed to have been paralyzed by West Nile since then.

Twila Jean, whom everyone calls TJ, barely remembers falling ill. Her memory remains fogged by the sudden high fever that attacked her on a trip between their home east of Baton Rouge and Newnan, where Joe's son lived.

Joe and TJ had been married for eight years. They were headed for a July Fourth family weekend, to scoop up two grandchildren and take them away for a monthlong visit. It was a final holiday before the start of a new life: The Starkeys planned to spend several years doing mission work.

Instead, TJ, who was then 50, spent 21 days in Emory University Hospital's intensive care unit, 47 weeks in hospitals in Georgia and Louisiana, and six months in a nursing home.

"I remember the white coats, lining up around the bed," she said. "I couldn't understand what they were looking at."

The paralysis moved up her body so swiftly that Joe, then 58, had to carry his wife into the emergency room. It took four months before TJ could take a sip of water, seven months before she was strong enough to urinate without a catheter, and 10 months before she was allowed to wear real clothes. She has been back at home since December 2003.

Her illness has rerouted their lives. When TJ fell ill, the Starkeys were living temporarily in a trailer on land that has been in Joe's family since the early 1900s while they renovated his grandparents' farmhouse. But the narrow old house would never accommodate a wheelchair; they tore it down and settled for the trailer. Joe ripped out the carpet, to make it easier for her wheelchair to roll, and he and TJ's two sons built her a ramp.

Joe had planned to fund their early retirement by taking short-term contract jobs at the huge chemical plant where they first met. Instead, he is TJ's primary caregiver and coach, and raises money by trading stocks from home.

"The way I was raised, you provide," he said. "To not be able to work, it wears on me."

This summer is the sixth for West Nile virus in the United States. As of Friday, there have been 1,309 cases of West Nile and 35 deaths this year, most of them in the West. The mosquito-borne disease arrived in New York in the summer of 1999. It sickened 62 people that first year, killing seven of them. Then it picked up speed, moving north, south and then west: Between 2000 and 2003, there were 14,105 cases of the disease and 559 deaths.

Those are the known cases. They were recognized by a suspicious physician or had severe symptoms --- high fever, confusion, severe weakness, brain swelling --- that were impossible to miss. The CDC estimates that for every serious case of West Nile, as many as 150 milder cases are never diagnosed.

Agency researchers have gauged that, among the most serious cases, 10 percent suffer paralysis. If that estimate is correct, then about 46 Americans --- one-tenth of this year's 461 most-serious cases --- have been paralyzed by West Nile this summer.

No one can say yet what their prognosis is.

"Our preliminary information suggests that there will be varying amounts of improvement in the short term," said Dr. James Sejvar, a CDC neurologist studying West Nile paralysis. "For the long term, time will tell."

Slow, uneven progress

TJ's recovery has been a slow slog, from improvement to setback to improvement to plateau.

She was discharged from Emory's Wesley Woods rehab hospital in December 2002 and transferred to North Oaks Health System in Hammond, La. There she began working with Barrett Willis, an occupational therapist and Army veteran in his early 30s whose first child was born just before he and TJ met.

"When my daughter was 8 months old, she already had better control of her trunk and her head than TJ had," he said. "It gave me an inkling of how to work with her."

West Nile paralysis resembles polio; autopsies on some of the patients who have died have proved the diseases destroy the same nerve cells. But Willis is too young to have ever met a polio patient. He designed treatments based on what TJ seemed to need most.

Willis got down on floor mats with her, pushing her floppy limbs to stretch them, and perched her sideways on a swing to force her to hold herself upright. He sent her to swimming therapy. Standing in the deep end of a local pool, with weights on her feet and water up to her chin, she walked for the first time in more than a year.

This summer, TJ began horse therapy. Twice a week, Joe drives her an hour to MeadowView Stable in Baton Rouge, where she is the only adult patient among a dozen disabled children.

One recent morning, she stretched her legs carefully across Buck, a mellow 10-year-old quarter horse the color of toast. Two therapists held her in the saddle; Krista Owens, the stable owner and an occupational therapist, led them slowly around a corral.

The hope is that the rocking of the horse's gait will remind TJ's muscles of the motions of walking, encouraging new nerve branches to grow.

When the procession stopped in mid-paddock, TJ slowly lifted one hand and then the other from supports on the harness. She sat braced for several seconds, trying to straighten her shoulders and back, and then collapsed. She was breathing hard and drenched with sweat.

"It's more work than jogging ever was," she said. "I'm exhausted."

Searching for meaning

The Starkeys are religious people. Since they came home, friends have prayed for them and over them, laid hands on them, anointed them with oil.

Joe and TJ read the Bible daily. They are looking for relief from their troubles, but they are also looking for an answer. TJ is convinced that her illness nearly killed her. She believes there must be a reason she was spared.

"Maybe the mission work we were planning on wasn't the right thing to be doing," she said recently. "Maybe I'm meant to work with the disabled. Maybe that's why I'm disabled myself."

She has complete assurance that she will recover. Friends have told her so; they tell her that God has prompted them to say it. "You don't have a choice in the matter," a visitor told her one day in the nursing home. "So many people are praying for you that you have to get well."

Several times a day, TJ practices standing. Joe positions a walker in front of her wheelchair so she can lever herself erect. She stays upright as long as she can, savoring the feeling of her weight bearing down on her feet.

To distract herself, she gazes at photos of her grandchildren that are taped to the wall of her bedroom. In the center of the pictures is a Bible verse that has sustained her since she first fell ill.

She has read it so often that it is engraved on her memory, but she keeps it pinned on the wall, like a bill to be paid or a promise that must be fulfilled.

The verse is from Isaiah:

"They that wait upon the Lord shall renew their strength; they shall mount up with wings as eagles; they shall run, and not be weary; and they shall walk, and not faint."